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RESEARCH

From frustration to coping with caring for death by nurse technicians

Da frustração ao enfrentamento do cuidado para a morte por técnicos de enfermagem

Desde la frustración al afrontamiento del cuidado a la muerte del personal de enfermería

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ABSTRACT

Objective: to understand nurse technicians' experience with caring for the death of terminal patients in ICUs and to configure a theoretical model. **Method:** qualitative study with theoretical saturation when analyzing the 10th non-directive interview, having as reference Grounded Theory, Symbolic Interactionism and Bioethics. **Results:** the core category - from frustration to coping with dignified nursing care for finitude: the acceptance of death as a therapeutic and intervenient component - emerged from the comparison of the sub-processes: when the nurse does not feel prepared for caring for death, accepting death as a therapeutic phenomenon and developing coping strategies. **Conclusion:** according to Symbolic Interactionism, a novice professional's frustration in caring for an individual for death is related to his/her interaction and interpretation of the situation as he/she feels prepared only to care for individuals for life.

Key words: Death; Nursing Care; Intensive Care Units.

RESUMO

Objetivo: compreender a experiência de técnicos de enfermagem com o cuidado para a morte de pacientes terminais em UTI e configurar um modelo teórico. **Método:** estudo qualitativo, com saturação teórica mediante a análise da 10ª entrevista não diretiva, tendo como referenciais a Teoria Fundamentada nos Dados, o Interacionismo Simbólico e a Bioética. **Resultados:** a categoria central - da frustração ao enfrentamento do cuidado digno de enfermagem para a finitude: a aceitação da morte como componente terapêutico e interveniente - emergiu da comparação dos subprocessos: não se sentindo preparado para o cuidado para a morte, aceitando a morte como um fenômeno terapêutico, desenvolvendo estratégias de enfrentamento. **Conclusão:** segundo o Interacionismo Simbólico, a frustração do profissional iniciante em cuidar da pessoa para a morte está relacionada à sua interação e interpretação da situação, por sentir-se preparado somente para assistir a pessoa para a vida.

Descritores: Morte; Cuidados de Enfermagem; Unidades de Terapia Intensiva.

RESUMEN

Objetivo: comprender la experiencia del personal de enfermería con el cuidado a la muerte de pacientes terminales en UTI y configurar un modelo teórico. **Método:** pesquisa cualitativa, con saturación teórica a través del análisis de la 10ª entrevista. Los referenciales son la Teoría Fundamentada en los Datos, el Interaccionismo Simbólico y la Bioética. **Resultados:** la categoría central - desde la frustración al afrontamiento del cuidado digno de enfermería para la finitud: la aceptación de la muerte como componente terapéutico e interviniente - emergió de la comparación de los sub procesos no sintiéndose preparado para el cuidado a la muerte, aceptando la muerte como un fenómeno terapéutico, desarrollando estrategias de afrontamiento. **Conclusión:** según el Interaccionismo Simbólico, la frustración del profesional iniciante en los cuidados de la persona a la muerte está relacionada a su interacción e interpretación de la situación.

Palabras clave: Muerte; Cuidados de Enfermería; Unidades de Cuidados Intensivos.

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INTRODUCTION

Technical and scientific advances have contributed for human longevity, but, at the same time, have also proven themselves challenging for the care of people at the end of life. This occurs mainly at Intensive Care Units (ICUs) scenarios, in which professionals constantly face ethical dilemmas related to maintain or not life support.

The decision making process regarding suspension of life support in terminal patients at ICU is subsided by international directives. However, there is great variability of those decisions at different countries, due to culture, religion, legislation, the structure of service and resources availability on the ICU, condition severity, prognosis and the personal life quality, as well as the professional decision. Such variability does not happen only from country to country but also from institution to institution and even among professionals of the same unit[1].

In Brazil, after discussions between physicians, other health professionals and Bioethics scholars, the Federal Council of Medicine (CFM) published in 2006 the Resolution 1,805, intending to regulate orthothanasia:

> In the terminal phase of severe and incurable infirmities, the physician is allowed to limit or suspend procedures and treatments that extend the infirm life, ensuring the care needed to relief symptoms that lead to suffering, in the perspective of integral assistance, respecting the patient will or his/hers legal representative[2].

Although this Resolution had been grounded over the Constitution of the Federative Republic of Brazil, Federal Justice revoked it by considering that the CFM does not hold power to regulate life. This is an unavailable right and no one is allowed to legislate about it, without a legal process of exclusive competence of the National Congress (Public Civil Action no. 200734.00.014809-3, of the 14th Federal Court)[3].

In 2009, with the publishing of Law Project 6715/2009[4], altering Law-Decree 2,848/1940, the illegality of orthothanasia on the Criminal Code was excluded.

It is important to highlight the non-prohibitive and non-punitive character of the CFM Resolution. This Resolution had the function to indoctrinate an ethical-professional recommendation[5]. Besides, there are practical and bioethical implications related to Resolution 1,805/06, as the risk of hospitalized patients in public hospitals to be compelled to accept the procedure. The real motives for this are to make space for other people with a chance of cure, to reduce costs with unneeded procedures or the risk of diagnosis error, beyond the fact that the possibility of new techniques or interventions that may cure the patient always exists[6].

Orthothanasia thematic draws attention to the priority of life quality and a decent death for the patient[7]. Etymologically, othothanasia means a proper death, i.e. to not artificially extend the process of death. It includes medical practices related to not to offer vital support and not to perform resuscitation maneuvers in patients that do not have a cure prognosis. Orthothanasia practice, therefore, aim to follow the terminal infirm for a painless death, without using disproportional methods for life extension[6,8].

In opposition to orthothansia is dysthansia, which means to extend life at any cost. This implies the exaggerated extension of a patient's life. The performance of useless interventions may bring severe pain and extend the process of death[9-10].

Euthanasia, in its turn, is synonym of painless, harmonious death, or even, death without pain or suffering[10]. This practice has the purpose to end the life of those who do not have conditions to live in a decent way[11]. Euthanasia's goal is not to kill, but to put an end on the extension of a physical and emotional exhaustion state.

In a terminal event, the most common way to limit life is cardiopulmonary arrest, which results in a sudden and unexpected termination of ventricular mechanical activity. This activity is a severe event and the quickest way to revert it is cardiopulmonary resuscitation (CPR). The do-not-resuscitate-order (DNR) may be indicated for certain patients without prognosis of cure[8]. However, such situation generates doubts for patients and families, and ethical dilemmas for the nursing team[12].

In ICUs, it is common to see patients depending on technological resources to support life[1], in many cases without prognosis[10].

Besides that, on the daily routine of this service, health professionals come across with the difficult situation to take care of patients without therapeutic possibilities. Some research highlight ethical dilemmas lived by the nursing team related to terminal patients: values diversity, uncertainties about the terminal condition and intervention limits to extend patients' lives, non-acceptance to extend death by the patients' family, lack of explanation from the family and the patient[13-14].

Besides that, the association between pleasure and suffering for those professionals makes them value the need to demonstrate affection and dedication when dealing with pain and suffering of patient and relatives[15]. The DNR is only well accepted by the nursing team in cases of terminal and suffering patients[12].

Brazil's Federal Nursing Council (COFEN), a supervisory and regulatory agency of professional practice, forbids the euthanasia technique. The nursing professional is responsible to respect, recognize and perform actions to ensure the right to the person or his/her legal representative to take decisions about his/her health[16].

Considering:

a. The context of nursing practice on Brazilian ICUs scenery in which technicians are the ones who contribute the most for execute care plans, under the nurse responsibility[17];
b. The lack of researches exploring the perspective of nursing technicians about care with death of terminal patients;
c. The end of life as a polemic object on the Bioethical area.

A question remains: How is the perspective of nursing technicians about care with death towards terminal patients in ICUs?

The development of this research intended to contribute to deepening the knowledge about experiences of nursing technicians with the process of monitoring death, subside professionalizing nursing training of average level, as well as permanent education and mental health, aiming to improve the quality on the assistance given to patients without therapeutic possibilities in ICUs. For that, the goal is to comprehend the experience of nursing technicians under the monitoring of death in terminal patients at ICUs and to configure a theoretical model to represent it.

METHOD

It is a qualitative research initiated after the approval of the Ethics Committee Research and the acquisition of the free and informed consent by nursing technicians of an ICU in a teaching hospital in the countryside of the state of São Paulo, Brazil. The hospital is associated to the Brazilian Unified Health System (SUS), covering the service for a population of 1.5 million. There are 415 beds, 52 being in ICU (30 adults, 15 newborns and 7 pediatric). From the 30 beds for adults in the ICU, 15 belong to central ICU, 6 to coronary and 9 to emergency room ICU. The ICU where the study was performed has a team of 12 physicians, 12 nurses and 19 nursing technicians.

The gathering of data occurred on September and October, 2012, through non-directive interviews technique, holding a leading question: how has your experience to assist terminal patients been at ICU?

The interviews were recorded on video in places that preserved the privacy and anonymity of the individual's information. After the full transcription was performed, omitting any information that could identify the interviewees. The data were submitted to an analysis following the methodological reference steps of the Data Grounded Theory[18]:

- Microanalysis: detailed analysis line by line, required to generate initial categories (with its properties and dimensions), suggesting associations between themselves and a combination of open and axial codification;
- Open codification: analytical process through which the concept, properties and dimensions are identified and discovered on data. It is allowed to conceptualize the grouping process of items similar, according with defined properties and giving the items a name that means this jointed connection. During conceptualization, data quantities are greatly reduced. A concept is an abstract representation of an event, object, action or interaction that a researcher identifies as being significant to the data. Categories are concepts of the data that represent phenomena. Concepts start to build up when the analyst initiate the process of grouping or classifying in more abstract terms, into categories;
- Axial codification: the process to relate categories to their subcategories according to their properties and dimensions, systematically. This analysis stage is important for theory construction;
- Selective codification: an integrative process to improve the theory. On integration, categories are organized around a main concept through several techniques: to describe the history, using diagrams, rate and review notes.

Respecting the proposed steps for this reference, a theoretical saturation analyzing the 10th interview with nursing technicians was obtained. The theoretical model immersed on the analysis process was discussed on the light of theoretical reference of symbolic and bioethics interactionism.

RESULTS

Characterization of the research actors

From the ten nursing technicians working on ICU that were part of the study, 8 (80%) were female, and two (20%) male, with average age of 31.8 years, 8.7 years since graduation, 8.1 years of professional experience and 6.4 of working with patients in critical state.

Experience of the nursing technicians in the ICU

From the data analysis, the experience of nursing technicians with the process of taking care of people facing death in the ICU was understood. The identified categories and theoretical associations established enabled the development of an analytical and explanatory process of actions and interactions that compose the process of handling this situation, having 3 sub processes: not feeling ready to face death, acknowledging death as a therapeutic phenomenon; development of coping strategies (Box 1).

Box 1 - Categorias e subcategorias que compõem os subprocessos da experiência do técnico de enfermagem com a morte na UTI, Botucatu, Brasil, 2012

Categories (Subprocesses)	Subcategories
A. Not feeling ready to face and cope with death	
B. Acknowledging death as a therapeutic phenomenon	
C. Development of coping strategies	C1. Defending the maintenance of minimal care
	C2. Distancing affectively from the patient and family members
	C3. Leaning on religiosity

"Not feeling ready to cope with death" is how nursing technicians access their own conditions, facing the dilemma lived during the beginning of professional experience in the ICU. Coming from a training directed towards helping people to live, they are faced with coping with patients for dying. For such reason, they are self-appointed as novices in this phase, for letting themselves to get emotionally involved, walking in the shoes of the patient or family members. However, those facts keep them motivated to continue committed on the promotion of full care, as they were capable of assist them to reestablish health and life. This phase is recognized as one of great psychical suffering, for the professional feels powerless and frustrated facing a situation in which they do not have control, despite all the effort made.

> *In the beginning it was harder, I got too involved with the patient* [...]. (TE2)

> *It was challenging, when you assist a patient to live, we end up walking on his and his family members shoes* [...]. (TE6)

> *When I got to the ICU* [...], *I wanted to see the patient out of that situation. As time went by, we see that the patient does not have a prognosis, that he will not get better at all* [...]. (TE1)

In face of the need to adapt to the new practice context, nursing technicians reflect about their experiences on the ICU, and also how would it be to have a relative in the situation of the patients they assist. Through this movement, it is possible to notice that the best way is to align with more experienced medical teams and co-workers. This is the second experiential stage, named "acknowledging death as a therapeutic phenomenon", for terminal patients, their family, and also interprofessional teams. The teams care for and share the suffering of the terminal patient, and also of those patients waiting for a vacant bed. The accomplishment of the medical order of not trying reanimation procedures, in case of cardiopulmonary arrest is fully admitted, especially for older adults. However, it is even harder when facing a young person, as related below:

> *Nowadays, I think it is better to not invest and let the patient go* [...]. *It is very hard to stay on bed in a vegetative state, depending of others, knowing you won't get better.* (TE1)

> *The hardest thing is when the patient is too young and you are aware that there is no prognostic.* (TE5)

> *Today I feel psychologic prepared for taking care of patients facing death.* (TE 7)

> *When the medical team decides not to invest, we end up a bit upset, on the other hand, we see that it is better for the patient, and also for the person waiting for a bed vacancy.* (TE10)

The nursing technician assists the patient to die without interfering in his/her moral, ethical and religious values, cushioning the suffering that shall come. Thus, the third stage of the experience beings, "development of coping strategies". The nursing technician assists "defending the maintenance of minimal care", aiming to ensure a decent death, once the death is a plan from God and not of man. Such care involve to continuing feeding, hydration, hygiene, and medication administration resulting in sedation and temperature control, according to the statements:

> *I think the right thing to do is to invest on the patient, his process of dying does not mean he shouldn't have access to taking medicines and bathing. I think at least the very basic should happen. But, in the case of reanimation, I guess if there is nothing left to do, there is nothing left to do.* (TE3)

> *We resent a bit, because sometimes the doctor comes and says the patient is a NRO* (No Reanimation Order). *Then you see the patient is burning with fever and there is no longer medication. We would like to have it, not for healing procedure, but at least to relieve his pain. I think it is fair to sedate, feed and give temperature control medication, here the investments are interrupted when this happens, the patient only gets the diet and sedation, the antibiotics are interrupted. I am against it. I think they are entitled to die with dignity.* (TE5)

> *Minimal care means the person not feeling pain, to respect the patient, not dying in apnea, but to change decubitus to avoid formation of ulcers and to bathe.* (TE8)

Although nursing technicians agree to assist the patient for death, this conscious decision does not fully rid them of facing suffering during their experiences. For this reason, there is a second strategy they can use to attempt to not place themselves on the role of patients and their family during this process. This ability is only reached as the professional acquires experience when living the death context repeatedly. The adoption of an attitude named "distancing affectively from the patient and family members" helps when receiving the medical order not to reanimate in case of cardiopulmonary arrest. This decision helps to decrease emotional involvement towards the situation, avoiding interferences outside the work scenario.

> *At the beginning, the assistance is for the patient to live, we walk in his and his family shoes, but with time you get used to it, it becomes a routine.* (TE6)

> *I think that for the time I am working here, I have seen so many that it became a regular process. At first I thought it was difficult to see the person suffering, but after a while you get used to it. When the patient stays more time here, you get more attached, but when the doctors say that there is no prognosis, then it gets easier.* (TE3)

> *It is difficult but seeing it so much, you become less sensitive.* (TE4)

> *Today, I think I turned into a cold person. I may suffer in that moment, but then I turn my back and already forgot it. I feel prepared to take care of terminal patients because I've been here for 10 years.* (TE8)

In this context, those who believe death is a plan of God and not of men, state that they "lean on religiosity" as a third strategy to face suffering when assisting a terminal patient. In this moment, they raise their thoughts to a higher supernatural Being, omniscient and omnipotent, to relieve the pain to all involved on the scenario: patient, family members, and caretakers, as stated:

> [...] *there comes a time when I ask to God to take them [away], because the suffering is way too much for the patient and the family.* (TE2)

> *I believe who makes this choice is not us, but God.* (TE5)

Realigning the components forming subprocesses, it is possible to find out a central category assigned to cover it, constituting then the experience process named as: frustration when coping with decent care for finitude: acknowledging death as a therapeutic and intervenient component. This analysis was submitted to the evaluation of the individuals, and they considered it represented their experiences faithfully.

DISCUSSION

The theoretical model related to the experience of the nursing technician when handling terminal patients on ICUs signalizes the need to recognize death as therapeutic in cases of people who do not have any life possibilities. Having this recognition configured as an intervenient component for the technician to transpose imposed barriers when dealing with the event.

According to the Symbolic Interactionism, actions are caused by an active process of decision-making of the individual, involving the definition of a situation, in its turn, the self-interaction and others. Therefore, the subject defines the situation, which is essential to guide the action[19].

For this reason, novice nursing technicians on ICUs lives the frustration of assisting terminal patients, because they were academically trained to assist the patient to live. When facing the experience of handling with death, they are disappointed, believing they failed their training of assisting towards healing.

Despite the lack of studies about experiences with death in ICUs only for nursing technicians, research involving interprofessional teams (medical and nursing) support the results of this study. We highlight the need to train ICU nurses on coping with the end of life, developing abilities to support patients and family members who are living through terminality[20]. The success of the work depends on the training of healthcare providers[21].

Besides that, we also highlight the importance of establishing and following directives and consensual assistance planning for end-of-life care, involving team members, patients requests (if they have autonomy and conditions for this), and family members for the assistance to be less aggressive. This approach of shared decision making improves the quality of service and the work environment[1].

The literature shows that the exaggerated extension of death, submitted to an intense process of pain and suffering, extend the patient's agony if there is no possibility of healing. Thus, death and suffering would be extended, and not the patient's life[6,9,12,22].

The theoretical model resulting from the study points outs that the nursing technician will only develop coping strategies for the end-of-life care when interpreting death as therapeutic, as a necessary closure for terminal patients that do not have chance of survival. In this case, death is seen as therapeutic for the individual, family and members of the healthcare team, from a reflexive process in the professional and familiar experience. It is on the daily life practice that the psychological competence for coping with this situation arises.

This finding was also highlighted by research carried out only with nurses, as well as nursing professionals. It is observed that the longer the time of employment of the nurse, the better he/she is prepared for dealing with matters related to end-of-life care[21,23]. Likewise, the more involved with the patient and family, the more significant the death becomes to the professional, and death predictable situations were less traumatic[24]. Such feelings also emerged on professional nursing experiences regarding a deceased patient. In this case, the most significant experiences were related to the first contact with death, existence of emotional bonds and age of patient at the time of death[25].

Some studies show that the acceptance of death on its right time is a point of view of nursing, not only because it is part of life, but also because nursing is a profession that emphasizes sympathy, accommodation and human care. This is a differential from medical training, which focuses on healing and reestablishing health[8].

When interacting, the individuals become social objects to one another, they use symbols, self-guide, engage in mental actions, make decisions, change directions, share perspectives, define the situation and assume another person's role[19].

Nursing technicians recognize death as a therapeutic event and feel prepared to assist terminal patients. For this, they realign with medical teams and experienced coworkers. Besides that, nursing technicians lean on strategies of moral, ethical, and religious values. Among these, the maintenance of minimal care, grounded on the religious concept of death being a plan of God and not of men. Beyond that, when medical teams are making decisions not to invest in procedures of reanimation, the posture of psychological detachment is adopted, i.e., distancing emotionally from the family, aiming to soothe their own suffering.

Nursing professionals of ICUs look for a refuge on their beliefs and values to bear the psychical suffering generated by the death of patients[26]. Religion appears as a significant factor of attitudes towards death and assistance during the end of life for patients, family members, and also professionals[1].

In this study, nursing technicians defend the need to maintain minimal care as sedation, feeding and bathing. They are against the non-offer of antithermic and and antibiotics for patients who have medical indication of not be invested on. This speech is supported by the study that affirms that assistance of terminal patient must cover physical, psychological, and social needs. The personalization of assistance, promotion

of assistance, preparing procedures and adopting actions for pain and discomfort relieve, including family members on the assistance process[27].

It was considered a limitation in the present study to involve nursing technicians of only one ICU. However, it could facilitate comprehension of those professionals' experiences, what are the similarities with nurses' experiences. There are several directives to subside the decision making shared in terminal situations. Such directives favor life quality of patients, family, and professionals. However, the buildup of competences and abilities for the assistance during the end of life still is configured as a challenge on the training for nursing profession, both in high school and higher education.

FINAL CONSIDERATIONS

The development of this research has allowed to understand the experience of nursing technicians working in ICUs, regarding care with terminal patients. It was verified:

- The difficult to face death when starting the career, once they did not feel psychologically prepared, reporting the training focused only in life care, leaving aside issues about death;
- Strategy creation of personal coping, due to not involving emotionally with the patient and family members, searching to avoid personal suffering;
- To accept death as a therapeutic event due to professional practice experience;
- To disagree with the euthanasia practice, considered a crime by the Brazilian law, grounded specially on ethical and religious concepts;
- The defense of maintenance of minimal care and accepting death in its right time, i.e., orthothanasia.

At last, we suggested the engaging of assistance and professionalizing nursing training institutions in a continuous way to train these professionals to face care related to terminal patients.

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